In 2004, the National Hemophilia Foundation launched the National Youth Leadership Institute (NYLI) at NHF’s 56th Annual Meeting in Dallas, Texas. The Institute was created to foster the development of leaders and to help NHF Chapters across the country build strong youth programs. The Institute has specialized programs for youth at each stage: kids, teens and young adults.

NYLI Mission

Youth Leaders are composed of dedicated, ambitious leaders [many affected by bleeding disorders] who work to create continuity in local bleeding disorder communities. Youth Leaders help foster a sense of unity through the sharing of common experiences and establishing the foundation for future generations. Our awareness, knowledge and advocacy empower Youth Leaders to pass on the torch of passion for future leaders [in the bleeding disorders’ community].

NYLI Was Created To...

- Provide young adults with leadership and problem-solving skills;
- Create the next generation of leaders both locally and nationally;
- Help Chapters start or enhance local youth programs;
- Identify and reach increasing numbers of underserved youth;
- Provide a mechanism to educate youth about major problem areas and good health practices.

NYLI Is Composed Of...

Young adults, ages 18-25, who have demonstrated leadership skills in their community. After participating in NYLI training, Youth Leaders are responsible for implementing youth events focused on prevention/self empowerment in their local areas. Mentors from local chapters provide guidance and support.

Julia McDougal, 17
Chapter: Utah Hemophilia Foundation
Hometown: Orem, Utah
Hobbies: Playing the harp, cello, and piano, singing and dancing
At age 13, I was diagnosed with von Willebrand disease (vWD). I decided then that I could take my illness and use the experience to spread awareness and to help others living with bleeding disorders. I served as a camp counselor for the Utah Hemophilia Foundation’s summer camp, Camp Valor. I have lectured at Brigham Young University’s Health Science Classes on vWD. I served on the Primary Children’s Consumer Advisory Board, and currently serve on the Board of Directors for the Utah Hemophilia Foundation. I was also featured on a local Channel 2 News, “2 Inspire” program focusing on my active life with vWD.

continued on page 4
Each spring, we introduce our readers to the HPPS participating companies for the coming year!! Each of these companies provides pharmacy and home supportive services to local patients affected by bleeding disorders and has qualified as a 2008 participating company. Each company meets the very high standards of service set by Hemophilia Patient and Program Support, Inc (HPPS).

Meet these companies by going to our website hemophiliasupport.org and clicking on the companies’ logos. You will be linked directly to their site where you will find detailed information on the services that each company provides. Be an educated consumer and get the information you need to make informed decisions about what you need in a pharmacy.

If you or your family member has a bleeding disorder and you haven’t registered with the HPPS program in the past, fill out the enclosed HPPS registration and mail it back to the Chapter office. By registering, you will be informed of important issues and events throughout the year.

Hemophilia Patient and Program Support, Inc. is dedicated to providing support to patients and programs within the geographic boundaries of the DVC. Become a member today!!

We Gratefully Acknowledge the pledge of support from the following manufacturers for 2008.
On Saturday, May 3rd, teens, ages 15-20 will participate in the CEO Workshop in King of Prussia. This is an entirely new way to look at future careers, education and opportunities for young people. During the day, teens choose a job, a salary, a house and have a bank account, as well as a few unexpected surprises and challenges—just like in the real world. It’s a fun way to develop skills and talents while interacting with peers. A great big thank you to Baxter for bringing this great program our way. See you there!! For more information, contact the DVC (215-885-6500)!!

On Tuesday, May 6th, plan to attend our Annual Family Dinner at the Hilton Hotel on City Avenue. This year’s theme Working for our Community... Protecting the Present, Focusing on the Future, will provide updates on research leading to cures for bleeding disorders, an update on our state legislative initiative protecting access to care for patients and a wonderful tribute to Jamie E. Siegel, MD. Plan to attend this terrific night. Exhibit hall will open at 5:30 pm.

The "I Can Run Race," a 5K Race and Family Fun Walk will be held at the Hatfield Athletic Club in Hatfield, PA on Saturday, May 10, 2008. The fun starts at 9:00 am rain or shine!!! Refreshments, food, music and prizes galore!! We have always told our children never to say “I Can’t!!” We hope you will support this great event by crossing the finish line with us and saying "I CAN!!" Call the DVC office for registration information (215-885-6500).

May 13th, “Awareness Day” in Harrisburg. If you haven’t registered, call the Chapter right away!!! We need you!!

Monday, June 2nd!! Carlino’s Golfing for a Cure at the Edgemont Country Club in Edgemont, PA. Join us "on the links" for a spectacular day and the best food you have ever eaten, provided by Carlino’s Specialty Foods, Ardmore, PA!! A GREAT BIG “THANK YOU!!” to Laura and Pat Carlino and Kathy DiMichele for bringing this great event back year after year!! We love you!! Don’t miss it!!
My son, Bud and I attended the North American Camping Conference for Hemophilia Organizations (NACCHO) in Tempe, Arizona, January 25-27, 2008, representing the Delaware Valley Chapter. The weather was wonderful and we came back with many new ideas for our family camp. Many NHF chapters were represented along with organizations from around the world! We met representatives from Turkey, New Zealand, France, England, Scotland and Peru. While we were there, we also got some first-hand knowledge of what it is like to have hemophilia in other countries. It’s hard to believe, but there are still many places in the world where people with bleeding disorders never have the opportunity to go to a camp, much less have access to quality care or be treated with factor on a regular basis. We heard so many stories.

The weekend was filled with interesting speakers that covered a wide range of topics about camps. We learned so much and we were able to share the special way we do our own DVC Annual Family Camp in the fall each year.

Bud and I had a chance to hike a butte during the weekend. We left a permanent message from the Delaware Valley Chapter at the summit and took some fantastic pictures! We would like to thank the Delaware Valley Chapter for letting us represent our local organization at this great camping conference!!

Tim & Bud Fehr, Sumneytown, PA
The Challenges of Healthcare Inflation
By David Linney

Most change in life is incremental. Often, things change at a steady pace without our notice. For instance, many people with employer health insurance have been affected by the rising cost of healthcare. Don’t be caught unaware—increases in healthcare costs affect everyone.

Insurance Premium and Healthcare Inflation

Health insurance premium costs and healthcare costs continue to greatly exceed the rate of inflation, as seen in the following examples:

For the 158 million Americans covered by employer health insurance, the Kaiser Family Foundation Employer Benefits 2007 Annual Survey reported that the cost of health insurance premiums rose 6.1% in 2007 compared with a 2.6% increase in general inflation. In prior years, premiums rose at an even higher rate and there was an even greater gap versus the increase in general inflation. The report stated that the total annual cost of employer health insurance premiums (paid by the employer and the employee) average $4,479 for single coverage and $12,106 for family coverage. Since 2001, the cost of health insurance has increased by 78%, according to the report.

The U.S. Department of Labor in its August 2007 "Consumer Price Index Report for Urban Wage Earners and Clerical Workers" reported that the compound annual rate of inflation for medical care was 5.7% for the three months ended in August 2007. Medical care in recent years has consistently been one of the expenditure categories with the highest inflation rate.

Analysis of Health Inflation

The reasons for inflation are: an aging population, new medical technology, the high cost of drugs—particularly, new biotech drugs—and the rising costs of hospital care and physician services. These reasons, combined with the fact that healthcare is a profit-driven business, create a formula for continued inflation.

Employers have tried to manage health inflation by passing on a portion of the cost increase to employees in two ways: through increased payroll deduction or a reduction in benefits that offsets premium costs. The result is that employees have to pay more for health insurance premiums and out-of-pocket medical costs now and in the foreseeable future.

Some employers have also responded by sponsoring a high-deductible health plan. The Kaiser survey reported that 5% of employees in 2007, versus 4% in 2006, are obtaining health insurance through a high-deductible, consumer-driven health plan. These plans have high out-of-pocket costs. Their entry into the current position in the marketplace indicate that higher costs will be transferred to more consumers as the number of participants in these plans continues to grow. For employees, out-of-pocket costs today often include not only a deductible and co-insurance, but co-payments as well.

A Breaking Point?

There may come a time when employers may no longer be able to afford to sponsor a health insurance plan for employees. The Kaiser survey stated that in 2007, 60% of employers offered insurance, versus 61% in 2006 and 69% in 2000. Smaller employers are even more adversely affected by the high costs of health insurance than larger employers. The good news is that 99% of large firms with 200 or more employees continue to offer health insurance.

Some employees do not enroll in employer health insurance either because they cannot afford their premium portion or do not believe they need health insurance (in the case of some young workers). They want to keep their portion of the insurance premium cost in their own pocket. These employees add to the growing number of the uninsured and erode the insured pool that risk can be spread over for any particular insurance carrier. There are now 47 million US citizens without health insurance. Studies have revealed that some people do not seek medical care in a timely manner. They frequently end up going to the emergency room after a small medical problem becomes a larger one. Such employees are called the underinsured. Their numbers are growing.

What This Means for You

These trends mean that families and individuals with bleeding disorders will be paying more for employer health insurance premiums, as will every one else. It also means that you will be paying higher out-of-pocket costs than individuals without an expensive chronic health condition.

In addition, it means that more members of the bleeding disorders community may find it harder to obtain and pay for employer health insurance. They may have difficulty accessing needed bleeding disorder medical services because of inability to pay their portion of costs.

The future of employee health insurance is not bright. As premiums continue to rise at rates higher than inflation, the market will eventually reach price inelasticity—the point at which growing numbers of people will be unable to afford coverage.

It is important to know that the bleeding disorders community does have an infrastructure of support that helps to counterbalance the negative impact of inflation. It includes a number of assistance programs through state and federal programs; some NHF Chapters; and manufacturer factor product assistance programs.

The previous article was taken from HemAware, a publication of the National Hemophilia Foundation, January/February 2008 Issue.
PA Chapters Go to Harrisburg

A United Effort for Bleeding Disorders’ Awareness Day
May 13, 2008

On Tuesday, May 13, 2008 our friends from the Western PA Chapter/NHF will join members of the Delaware Valley Chapter in the state Capitol, as we visit with members of the Pennsylvania House of Representatives and Senate. The focus of our day is clear: we are asking for support for The Hemophilia Standards of Care Act, HB 1105 sponsored by Representative Lawrence Curry and SB 1030 sponsored by Senator Sean Logan. As families affected by hemophilia and von Willebrand Disease, we know that we must maintain access to:

1. all FDA-approved factor replacement therapies, no preferred medicines
2. the seven state-recognized hemophilia programs in Pennsylvania
3. the coagulation laboratories connected with our PA hemophilia programs
4. options in pharmacy and home supportive services

Plan to be a part of this very important day. Chapter buses will be available from Pittsburgh (on the west) and Plymouth Meeting Mall (on the east) to Harrisburg or you can drive. Either way, we need your help!! This is your chance to talk about how bleeding disorders have affected your life and your family. Our personal stories are very powerful. We need every member of the Pennsylvania legislature to understand why the provisions in The Hemophilia Standards of Care Act are important to us. And to do that, we need YOU!!!!! Call the Chapter office right away to register (215-885-6500)!! Be a part of history in the making!!

Region III Meeting Report Out...

By Hal Muschek

On February 28-29, 2008, I had the opportunity to attend the Annual Meeting of the Region III federally-funded Hemophilia Treatment Centers in Alexandria, VA on behalf of the Delaware Valley Chapter. There are 15 hemophilia treatment centers in Region III located in Pennsylvania, Delaware, Virginia, West Virginia, Maryland and the District of Columbia.

Presented first was an update on the continued growth in the total number of patients followed at Hemophilia Treatment Centers in Region III. There are now 3,400 active patients in the region, 5% of whom have inhibitors. We also learned of improvements in sharing information through the UDC (Universal Data Collection).

We were then given a very informative presentation on the diagnosis and treatment of von Willebrand Disease.

In the consumer’s focus group meeting, we discussed merger of all local chapters under the NHF banner to secure better funding and the introduction of Hemophilia Standards of Care Acts in states around the country. Also discussed was a proposal to establish a Standards of Service mechanism to ensure comprehensive services from pharmacies and home care companies.

On day two, we started with a presentation on hemophilic arthropathy. Included were the effects of synovitis in the onset of arthritis in joints, the importance of regular exercise to strengthen muscles that support joints and various surgical procedures to relieve symptoms.

Session two dealt with guidelines for prophylaxis in children with hemophilia. Data was presented showing the advantage of prophylaxis treatment when possible over episodic treatment.

Session three was a presentation on camp experiences for children with bleeding disorders, focusing on programs run in California and West Virginia. These allow nurses, physical therapists and social workers to observe how patients deal with their care, physical limitations and social interactions with their peers outside of a clinical setting.

Session four involved Hepatitis C management. Progression and mortality rates for HCV infections in both HIV positive and HIV negative patients were presented. Success rates with Hepatitis C treatments and new drug treatments coming in the next 5 years were also discussed.

Finally, thanks were expressed to Dr. Barbara Konkle, Sue Cutter, and Carolyn Johnson of Penn Comprehensive Hemophilia Center for the great job they have done running the Region III meeting for the last 12 years.
2007 FRIENDS OF THE DVC

FACT: In 2007, the Delaware Valley Chapter provided more than $352,000 in direct support to local patients and programs!!

In December, the Delaware Valley Chapter mailed the 2008 DVC Annual Request for Support to our members with the 2007 DVC Annual Report. We were amazed at the number of people in our area (and beyond) who responded so generously. Following is a list (incomplete and some anonymous) of those who donated within the designated categories. We extend a sincere thank you to our supporters...many who contribute several times during the year. Their support will help us to address the needs of patients and programs in 2008!! Thank you from the bottom of our hearts!! If you are able to respond, even in a small way, it’s not too late to support our great Chapter!! We depend on you!! Your donation is 100% tax deductible!!

President’s Club

Gold Star

$25,000, D. Mayer
$10,000, Anonymous
$10,000, University of Pennsylvania*

Special Donor

$1,000

Sam & Sue Campion
Joe Cohill
Joe Dalessandro
Joel Feldman
Anonymous
Anonymous
Ray & Peggy Kline
Keith & Suzanne Moore
Jim & Lynn Lindquist
Joe & Karen Pugliese

Shining Star

$300-$500

Leo Gianacopoulos
Kim & Jerry Hamstead
Lincoln Financial Group
Mr. & Mrs. Kenneth Phelan
Mona & Bud Salamone
Sue Stinger, in memory of Art Stinger
Anonymous
Anonymous
Walmart Foundation

Superstar

$125-$275

Kim & Keith Bayer
Steve & Cynthia Clowery
Pat & Pete Johnson
Anonymous
Mimi Kennedy
Ann T. Loftus, Esquire
Chris & Dana Marozzi
John & Ann Rogers
Anonymous
Anonymous
Andy & Shirley Serrill
Ann & Charlie Walker
Brigitte & Jim Weinrott

Star

$60-$100

Robert Beech
Martin Berndt
Maureen Budzilowicz
Edward & Carol Denny
John Greenwood
Bill Griffis
Tom & Christine Rowe
Kathy & Bob Sell
Birdye White
Shuang Zhao

Champion

$30-$50

John Bachman
John & Elizabeth Bogucki
Sheryl Dyner
Adam & Mindy Gusdorff
Glenn & Trish Kocher
Lentini Hearing Instruments
Sharon Littig
Michelle McManus
Charlotte Walsh
Xi Beta Pi

Supporter

$10-$25

Tracey Andre
Jerry Beasley
Joseph Buckley
Gladys Burke
Mr. & Mrs. Albert Caruso
Rose Daly
Howard Davis, Jr.
Paula & Barry Gartside
Ellhu & Annalee Ginsberg
Colleen Haley, in memory of David Schmitt
Stan & Renee Kiczek
Jeanine Krause
Josephine Larsen
Dennis & Coreen Macaluso
Lewis Martin

Russ and Becky Mundschenk
Oleg Nudelman
John Taraschi, Sr.
Marie Weber
Susan Weinstein
Patricia Wisch

*The Delaware Valley Chapter received $10,000 from the University of Pennsylvania as unrestricted support for patient programs in 2008.
Bleeding Disorder Legal Hotline

The Delaware Valley Chapter is pleased to announce the Bleeding Disorder Legal Hotline. This free, confidential phone line is manned by an attorney, Beth Sufian, in Houston, Texas. She has over 17 years of experience helping people with chronic conditions understand the laws intended to protect them regarding health insurance and school/work issues. This Hotline was initiated by the Lone Star Chapter of the National Hemophilia Foundation in 2006. Hotline callers have reported that the information was helpful and would have been difficult to find without the help of this service. The Hotline can provide information on the issues listed below:

1. Obtaining and maintaining private health insurance.
2. Obtaining coverage from insurers for medical treatment.
3. How a small business can obtain health insurance.
4. Legal rights regarding Medicaid & Medicare.
6. Appealing a denial of application for Social Security benefits.
7. Protection in the workplace from discrimination.
8. Family Medical Leave/Reasonable Accommodations in the workplace.
9. Insurance issues related to transitioning young adults.
10. Legal rights of children with medical conditions in the school setting.

The Bleeding Disorders Legal Hotline is open to people affected with a bleeding disorder and the medical professions that provide care for them. Quite simply, the Hotline is designed to bridge the gap between the laws and the people who need to know about them. Call 1-800-520-6154 and get informed.

The Hotline is recognized by the National Hemophilia Foundation as a valuable resource to the bleeding disorders community.

Planned Giving

When you make a future or planned gift, you help so many people. Remembering the Delaware Valley Chapter in your estate plans or will directly impacts the lives of people living with hemophilia and related bleeding disorders and their family members. You will also touch the lives of those who might someday be affected by a bleeding disorder. Arrangements can be made to leave a legacy in your will for the Delaware Valley Chapter. You can leave a specific amount or a percentage of your assets. Gifts may include, but are not limited to: stocks, bonds, guaranteed investment certificates, real estate, art and jewelry. Speak with your financial advisor about Planned Giving. Your gift can make a real difference!!

Delaware Valley Chapter Support Network

In an effort to increase our service and help to families in areas outside of the central Philadelphia area, we have established five branches of the Delaware Valley Chapter. The purpose of the branches is to help network patients and families affected by hemophilia and von Willebrand disease (VWD). If you are a patient or parent/s of a patient and would like to socialize with others who share your issues, please contact one of the following team leaders to get involved. These branches meet informally, in private homes, for social events and support. There is no charge for being involved.....just networking with families just like you!!

<table>
<thead>
<tr>
<th>Branch</th>
<th>Team Leader(s)</th>
<th>Contact Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Camp Hill Branch</td>
<td>Shannon &amp; Jay Penica</td>
<td>717-975-2897</td>
</tr>
<tr>
<td>Delaware Branch</td>
<td>Gail &amp; Luke Vannicola</td>
<td>302-378-1278</td>
</tr>
<tr>
<td>Lititz/Lancaster Branch</td>
<td>Lorie &amp; Brian Kerstetter</td>
<td>717-626-9679</td>
</tr>
<tr>
<td>Mount Carmel Branch</td>
<td>Jolene &amp; Sam Scicchitano</td>
<td>570-339-4137</td>
</tr>
<tr>
<td>Reading/Pottstown Branch</td>
<td>Tina &amp; Jeff McMullen</td>
<td>610-582-1731</td>
</tr>
</tbody>
</table>

These branches are not open to any person who works or has a family member who works for any industry or company directly or indirectly involved in products or services for patients with bleeding disorders.